Feasibility of a Family Centred Approach to ARV Treatment

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Presentation Outline

- Results from Pediatric Study
- The Care for the Family Centred Approach (FCA)
- Elements of FCA
- Issues in Study Design
- Concluding Remarks

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Pediatric Study: Purpose

- To provide information on current practices and perceptions relating to the treatment of children with HIV/AIDS
- To offer evidence-based recommendations regarding expansion of ARV access to children.

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Data and Methods

- Study period 11 April to 21 June 2005.
- A convenience sample of 16 sites in 5 provinces providing ARV services to children was included in the study
- Semi-structured interviews with 72 HCWs (Facility Managers; doctors, nurses, pharmacists, counsellors, social workers)
- Structured questionnaires administered with caregivers of children on ARVs (n=126)
- Initially we were targeting children less than 6 years but this was flexible

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Key Situation Analysis Results

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HIV and the Family

- 75% of caregivers said there was at least one person in the family infected with HIV besides the child
- 52% reported to be on ARVs
- 38% received treatment at the same clinic
- 86% of caregivers preferred that household members have their appointment dates together.
- In 88 % of cases, HH members knew of child's HIV status. Mother and grandma were the 2 most frequently mentioned relations that knew the HIV status of the child.

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Caring for Children

- During the week children live with biological mother (37%), both biological parents (23%), grandmother (15%), aunt (8%), the rest with grandfather, uncle, children's home and foster parents.
- During the day, largest % of children are looked after at crèche (48%) or by grandmother (14%).
- Mother and grandma carry the responsibility for taking child to clinic

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ARV Integration With Other Services

- 71 % of children referred to HIV clinic from a community clinic, 21% from in-patient ward, 6 % from a private practitioner, 2 % from PMTCT service
- 36 % of children receive treatment for other health conditions (TB, epilepsy, asthma) at same facility.
- The majority of children had received an HIV test because they were chronically ill (44 %) or hospitalized with a serious illness (40%) and another 6 % had been diagnosed with TB.

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The Current Model of Care

- The paediatric HIV and ARV services are ‘doctor driven’ especially for children younger than 6 yrs of age.
- The minimum team composition consisted of a paediatrician, nurse and pharmacist.
- The maximum team composition consisted of doctors, paediatricians, a clinical nurse, a nursing assistant, a phlebotomy nurse, a pharmacist, a pharmacists’ assistant, counsellors, a social worker and a dietician.
- Few ‘children-friendly’ environments had started at some health facilities
- Expansion of services will have to go beyond being “doctor driven”

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The Family Centred Approach (FCA)

A philosophy that puts the child and family at the centre of care, recognizing their strengths and weaknesses

Has been extensively promoted especially in North America, Australia and New Zealand wrt children suffering from chronic chronic conditions & education

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Elements of FCA at the Community

- *Information, Education and Communication about VCT & treatment*
- *Referral networks with local CBOs, women's Groups, HBC etc*
- *PSS*

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Why the FCA?

1. Concept of FCA resonates very well with modern trends (partnership, participatory relationships, empowerment for families & communities)
2. Nature of HIV/AIDS care (multiplicity, continuity & adherence issues)
3. Evidence of improved outcomes for children & families in terms of their psychosocial & physical needs
4. Increased family knowledge about HIV/AIDS, opportunistic infections, medication…for family members
5. Supported by concept of extended family & concept of HBC

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Elements of FCA at Health Facilities

- *Provider Training to Promote FCA*
- *Family Information, Education and Communication*
- *VCT & Treatment Referral*
- *Community Links and Referral*
- *Family Appointment Date*
- *Emotional Support for Providers*

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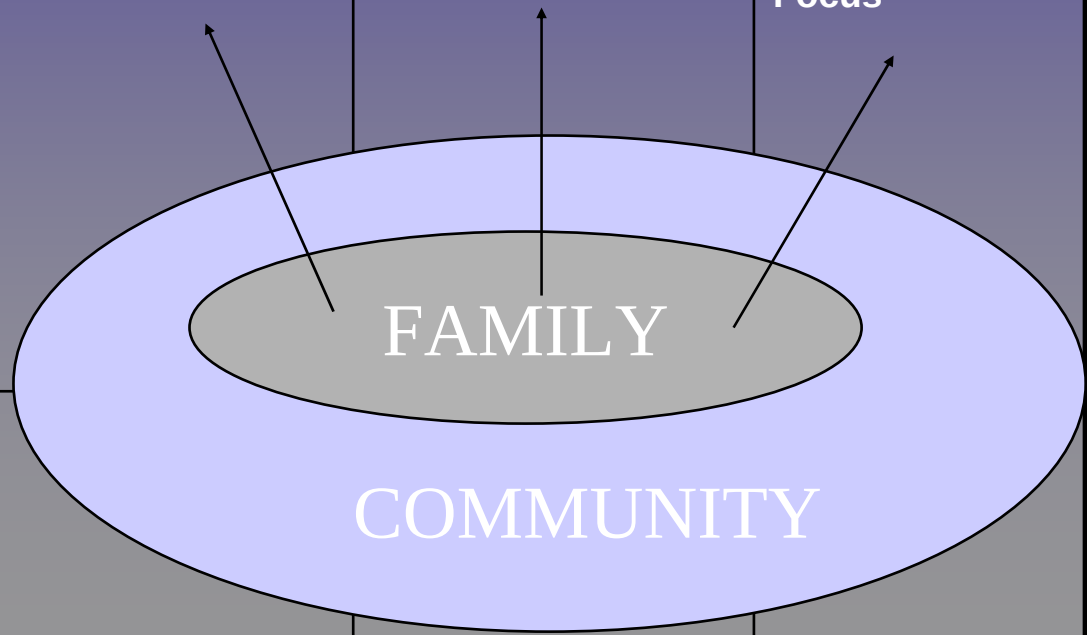
FRAMEWORK FOR FAMILY ENTRY

	FCA Elements	ANC	DELIVERY	PNC
HEALTH FACILITY	▪Provider Training ▪ Family IEC ▪Counselling ▪ Treatment Referral ▪ Family Appointment Date ▪Emotional support for providers	Mother Focus	Mother Focus	Baby/ Child Focus
COMMUNITY	•IEC (VCT & treatment) •Referral link with local NGOs, CBOs •Link with HBC •PSS			



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Issues in Designing A FCA?

- What families should participate in FCA (stigma, disclosure of status issues)
- What are the educational needs of the families and service providers?
- What are the Psychological Needs of Care for the Child & Family Members
- Can Family Group Counselling be considered?
- What links can be built between the family and the social capital in the community ?
- Service organisation in primary health care versus tertiary institution setting

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Outcome Indicators?

- Number of children diagnosed and put on ARV treatment
- Improved health outcomes in terms of morbidity and longevity of life.
- Better coordination of services for improved outcomes for families.
- Satisfaction with services
- Better adherence to treatment schedule for ARVS & other medications
- Stigma measures (feeling of isolation)
- Better mgt. of pain and symptom control
- Improved anxiety levels & spiritual wellbeing.

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Summary

- In terms of PEPFAR, targeted evaluation will assist us to get more children under treatment
- For OVC programs, some children are infected already and this will assist with treament and better health outcomes
- Perhaps we will define best practices that we can scale up

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Thank you!!

- WATCH THIS SPACE !!!!!!!!!!!!!

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Acknowledgements

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Horizons
Refining the response to HIV/AIDS through global operations research

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